

## *The AYJ Fund smiles ... connections ... cures*

***The mission of the AYJ Fund is to bring smiles to kids with cancer, to keep them connected to friends and school through technology, and to support the research of Gliomatosis Cerebri and other brain cancers to find a cure.***

Gliomatosis Cerebri is the rare type of brain tumor that Anna Yan Ji Arabia was diagnosed with at age 13. At the time of Anna's diagnosis, there was no research being done. We are committed to supporting new research now being conducted to find effective treatments and a cure for this devastating disease.



### ***THANK YOU FOR OUR "DOUBLE THE LOVE" CAMPAIGN***

We are so grateful to each and every one of you who blessed us with your love and donations to our AYJ Fund "Double the Love" Campaign to recognize Anna's 5<sup>th</sup> "Angelversary". We were overwhelmed by your support, generosity and creativity! We reached our



initial \$5,000 in matched donations, and our dear friend Carolyn Mandell offered a challenge to match additional donations. She did that and more! Anna's good friend Alyssa asked people to donate to the AYJ Fund in lieu of birthday presents and donated \$500, our friends at Balderdash ran a

Superbowl Football Square donating

their wine as prizes and raised \$500 also! Joe's friends from St Joe's class of '67 donated \$500, and we had donations in memory of family members and friends and so many other donations that touched our hearts. Our goal was to honor Anna's spirit and do something significant to make a difference for kids fighting cancer, and you certainly helped us to do that. Our donations totaled over \$ 20,000!! Thank you from the bottom of our hearts.

### ***WINE, CHOCOLATE & CRAFT BEER TASTING IN NORTH ADAMS***

The AYJ Fund had a very busy first quarter of 2018. We held our North Adams Wine, Chocolate and Craft Beer Tasting fundraiser on March 4<sup>th</sup> at the Freight Yard Pub. The event was our fourth in North Adams and so

many of our supporters came out to enjoy a wonderful selection of wines, craft beers, and of course delicious chocolates. Donna and Cristian from Balderdash Cellars poured a selection of their wines and FYP served nice wines as well. Andrew Crane shared his craft beers from Shire Brewery in Dalton and partnered with our bartender Jay Meehan who also poured beers from Wandering Star Craft Brewing, Bright Ideas Brewing, Scantic River Brewery, and Grazie Restaurant. We had delicious chocolates from Chocolate Springs and Goodnow Farms



Chocolates, as well as wonderful artistic cookies and desserts from Gimme Some Sugar of Pittsfield and the FYP. The event also offered a

silent auction, wine pull, and raffle. We are grateful to West Package Store, which helped us again with our wine pull. Thank you to Jess Renee, who provided beautiful music, including a song she wrote honoring our friend Carrick. Thanks to all who came out to the event, and to those who provided donations to the auction, wine pull and raffles and to all of our volunteers. It was both fun and successful!

### ***WINE, CHOCOLATE & CRAFT BEER TASTING IN BOSTON***

AYJ Fund took our organization on the road on April 7<sup>th</sup> to Oak Square Brighton, in Boston, where we held our 3<sup>rd</sup> Boston Wine, Chocolate and Craft Beer Tasting at

the Presentation School Foundation Community Center, which once served as Kathy's elementary school. Many of those who attended were former students also. It was a wonderful community reunion.



The AYJ Fund was honored this year to have four physicians and researchers from Dana-Farber Cancer Institute attend our event: Andrew Hong,

MD, Karen Wright, MD, Dr. Mimi Bandopadhyay, (Left to right in photo with Kathy and Joe), and Zachary Reitman MD. It was truly special. Dr. Mimi spoke beautiful words about how Anna touched each of them and influenced their work and how Anna was a pioneer patient in the area of precision medicine and inspired them to continue their research. She also read a message from Nathan Robison, MD, who was Anna's own NeuroOncologist at DF. He has since returned to California but sent these touching words about Anna ...

*"Every child, and every patient is special - but there are some who stand out - and then there are a few who are remarkably so ... and then there is Anna.*

*Forced to walk a dark and difficult road, she did so with incredible courage, and with an unquenchable, spunky sense of humor. Despite a horribly abnormal situation - she was committed to showing the world that she was still a normal girl. Confronted with bad news, her chief worry was invariably that she would fall behind on her homework... having to deal with all sorts of nasty treatment side effects - the only one that actually seemed to bother was losing her hair... She had two incredible parents who walked a dark road with her, finding joy and hope and humor in a thousand small ways along the path - it is because of their strength that she was successful in her aim: in a situation that was anything but normal - they made it possible for her to be a normal girl...Despite its brevity her life was full.*

*And her life was, and is, a gift... to many, including myself. It is a joy and privilege to have known her."*

*Nathan Robison MD*

Thanks to Gervais Ford, Kathy Sullivan, West Package Store and more for a great selection of wines, Jack's Abbey, Tuckerman's, Cambridge Brewing, Aeronaut and Down the Road craft breweries. We all enjoyed delicious treats from Blackbird Café, Goodnow Farms, Harbor Sweets, Putnam Pantry chocolates, and Nellio's our caterer. And we thank our many volunteers and so many others who donated such wonderful items to our fabulous Silent Auction and Chinese Auctions. A final thanks to PSF!

## LUCKY GRONK RAFFLE WINNER

And the winner of our signed Rob Gronkowski jersey



was ... Robin Laurendeau of Acton, a football fan from a family of football fans who was thrilled! Gronk has always been special to us since he visited Anna when she was at Children's Hospital. Go Gronk!! Thanks to all who took a chance and supported the AYJ Fund, and Dan Costa and Dunkin'

Donuts for their special donation.

## SMILES PROGRAMS Daisy & Cupcake

Our friend Daisy needed to travel from her home in Colorado to spend extended time in Georgia to participate in a new Clinical Trial. Being away from home is never fun, but for Daisy to be away from her dog Cupcake was even more difficult. Thanks to our supporters, the AYJ Fund was able to find a stuffed animal that looked just like Cupcake and sent it off to her at the Ronald McDonald House where she was staying. We were smiling too when we received this message from her Mom ...

*"You sure know how to make a girl feel better! Daisy loves Cupcake and she won't let her out of sight. Thank you so much. It was a very sweet gesture that deeply touched our hearts."*



And our favorite message when Daisy later texted ...

*"This is Daisy I Love My package 📦📦 thank you"*



## Tripp Tough

We have to agree ... Tripp is tough! He is only three years old and fighting Gliomatosis Cerebri, the same cancer Anna fought. His treatment included a stem cell transplant, which is difficult for any adult and so much more so for a little one. We sent Tripp a SMILES package to brighten his day and received a wonderful message back from his Mom ...

*"Hello Kathy and Joe/ AYJ fund! We would like to personally thank you for your gracious gesture! Our son LOVED the care package you sent!!! Today was a rough morning for our sweet Tripp dealing with fevers, nausea, mucositis, low blood counts, etc. Haven't seen the poor kid smile all morning until he opened your package!!!! We can't begin to thank you enough!!*

*Truly appreciate it!* 💙



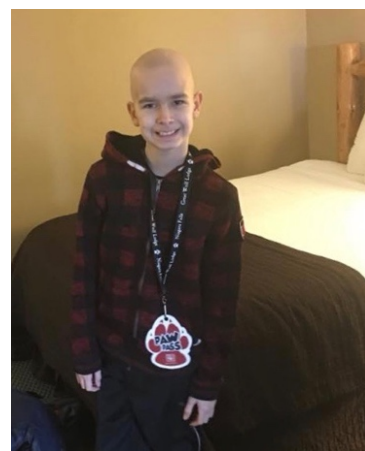
## Pillow Project



So many fun colors and prints and so many pillow cases! Thanks again to our super sewers who managed to find even more beautiful prints to brighten the days of the kids at the Jimmy Fund Clinic. This is Wally outside the Jimmy Fund Clinic before they distributed these wonderful gifts to the kids!

## Aidan's trip to the Indoor Water Park

Our buddy Aidan is also fighting Gliomatosis Cerebri. He was facing another round of radiation and a difficult chemo series and the AYJ Fund thought it was the perfect time for a fun getaway with his family. Aidan decided that an indoor water park sounded like fun. The AYJ Fund was able to plan a couple of days at the Great Wolf Lodge at Niagara Falls for Aidan and his family. It looks like he had fun!



## Valentine Treats

Our SMILES treats for the kids who were treated at the Jimmy Fund Clinic on Valentine's Day were Popcorn Containers with iTunes cards attached. We also provided a new iPad the kids can use when spending the day in the clinic. All of the gifts were a hit!





## Sending Spring Smiles

Every year we celebrate Anna's birthday by delivering spring SMILES to the Jimmy Fund Clinic for them to distribute to the kids being treated on April 9<sup>th</sup>. We



made sure our friend Cam had his specially delivered! This year we had great help from our shopper Elise who helped us find bright beach towels, flip flops and sunglasses which we wrapped up for the kids. After this long winter we all were ready for spring!



## Easter Bunnies

Easter came early this year and the staff and residents of Mt. Greylock Extended Care Facility made sure that it was a special time for the kids being treated at the Jimmy Fund Clinic. They cut, sewed and stuffed these



adorable fleece bunnies. It was a special project that the residents requested to do, after the stuffed bears they made last year were so greatly appreciated. One of the little patients Lucia is shown here with her beautiful bunny and her beautiful smile!

They were specially delivered with a little extra love by Mary Costa, Anna's Aunt and one of our AYJ Fund Board members. She was caught on camera and found on DF's Facebook page!



## AYJ FUND'S FIRST MCLA INTERN

This semester the AYJ Fund had an intern from MCLA working with us. Meghan DeLuca is not only an MCLA student, but also was one of Anna's best friends since early elementary school days. In an article in the Berkshire Eagle, Meghan was asked what it was like to be interning in memory of a friend and she responded "... in one word: fulfilling. For me it's bigger than just for Anna. I've had quite a few loved ones affected by cancer – so to be able to keep Anna's memory alive and also feel like I'm contributing to a greater good. It's fulfilling."

"People should continue to support the AYJ Fund, because it's not just in memory of a young life cut short. It's the memory of every person you've ever loved who was taken from you too soon. The AYJ Fund is a movement, not just an organization"

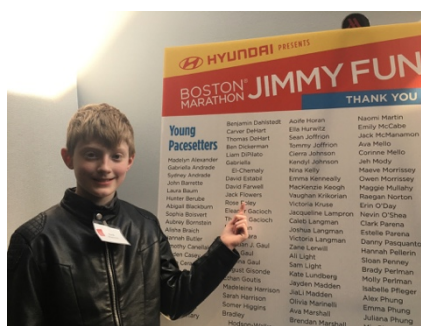


This photo was taken as Meghan received a tour of one of the brain tumor research labs at Dana-Farber by Dr. Mimi Bandopadhyay.

## ANNA'S ARMY'S YOUNG PACESETTER

Jack Flowers was recognized at the Jimmy Fund Walk

Breakfast for his achievement as a leading fundraiser in the Boston Marathon Jimmy Fund Walk. So proud to have him on our Anna's Army Team. Go Jack!

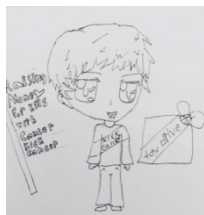




## JACK'S UPCOMING FUNDRAISER

*"My name is Jack Flowers and I want to help the Jimmy Fund care for kids with cancer... Please help me raise money and collect toys for both the Jimmy Fund and the AYJ Fund – both organizations that help kids who suffer from cancer."*

*Bake Sale and Toy Drive  
Memorial Day  
Mon, May 28, 2018  
8am - Noon  
3 Center St / Granby MA  
801-367-2388 (Laura)*



Donations can be made on the AYJ Fund website.

## MARK KIERAN MD PhD



From the day we met Dr. Mark Kieran at Children's Hospital Boston, we knew Anna was in good hands. Since we met, he has worked with us and helped to move research

forward at the international level for Gliomatosis Cerebri. Mark is now leaving Dana-Farber and we will miss him greatly. He has left us in capable hands with a group of researchers and physicians who are dedicated to assuring this research continues to move forward. We have much to be thankful for.

Mark THANK YOU for...

- ❖ Taking care of our beautiful daughter Anna Yan Ji as your own, through her most difficult days.
- ❖ Leading the advancement of understanding and research on Gliomatosis Cerebri globally.
- ❖ Committing to and convincing other physicians and researchers to direct research to include GC.
- ❖ Fighting for kids with Gliomatosis Cerebri even without a WHO Classification.
- ❖ Spending time to support, guide and teach the GC Global Community.
- ❖ Leading your team of NeuroOncologists at DF to provide expert care, compassion and even smiles.
- ❖ Always taking time to meet, to talk, and support our AYJ Fund work.
- ❖ Giving us a fabulous reason to visit Paris for the 1<sup>st</sup> International GC Conference.
- ❖ Your compassion, your dedication, and your friendship.

We have been blessed to have had you in Anna's life and in our lives,

*Kathy & Joe*

## CHILDREN'S MINISTRY BLESSINGS

The AYJ Fund was blessed to work with the Children's Ministry of the First Baptist Church of North Adams.

This group of young boys and girls attentively listened to the work the AYJ Fund does and worked hard to collect fun items to send smiles to kids who are undergoing cancer treatment. Their outreach project exceeded all of our expectations.



They did an amazing job and had fun filling AYJ Fund backpacks. They involved the whole congregation in their project and collected hundreds of items that we know the children spending time at the Jimmy Fund Clinic will love. Thanks to Morgan Kierstead for reaching out to us, and all of the teachers and families who were involved in making this so successful and fun!



## AYJ FUND SIGHTINGS



AYJ Fund Treats



Doris's AYJ Fund Pottery



Our favorite chocolates!

## BERKSHIRE COUNTY JIMMY FUND

Two great upcoming local Jimmy Fund events include:

Jimmy Fund Fishing Derby – June 2<sup>nd</sup> at Onota Lake Pittsfield. This event is held in memory of Harry A. Bateman and will include lots of prizes, fish and fun.

Jimmy Fund Golf Classic – June 13<sup>th</sup> at the Berkshire Hills Country Club in Pittsfield. This is the 35<sup>th</sup> Annual Paul Dowd Jimmy Fund Golf tournament with proceeds benefiting Dana-Farber.

Contact Kathy for more information.



## PRECIOUS MEMORIES



Heaven gained another angel and cancer warrior early this year. This is one of our favorite pictures from our AYJ Fund Corn Hole Tournament where Josh Sargent and his Mom posed with their great smiles. Fly high Josh!

## HEARTFELT DONATION

John Moffitt was a retired firefighter, a World War II Veteran, and a Purple Heart recipient. The AYJ Fund is grateful to his family and honored to be the beneficiary of his memorial donations. His service to others continues through the AYJ Fund spreading his love and more smiles to children with cancer.



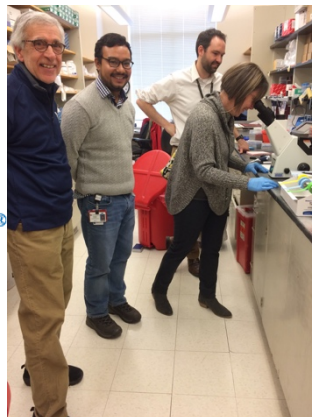
## THANKS TO WNAW



Kathy and Joe were guests on WNAW's Insight radio program early in March to spread the word about the AYJ Fund and promote the Wine, Chocolate, and Craft Beer Tasting we held in North Adams. We were able to share how the AYJ Fund helps children with cancer through Smiles, Connections and Cures. Thanks to Mike Garland and WNAW for this great opportunity!

## AYJ FUND SUPPORTING CANCER RESEARCH AT DANA-FARBER

In February, the AYJ Fund visited Dana-Farber Cancer Institute, met with Mark Kieran, MD, PhD, and also got a tour of one of the labs that is doing cutting edge resource on brain cancer. The brain tumor program



now has three labs, each focussing on a different area of research. Dr. Mimi Bandopadhyay leads the lab that focuses on DNA Single Cell analysis. We delivered a check for \$10,000 to continue this critical research, and thank all of our supporters who help us to fund this research through

our CURES program.

As we met with Dr. Kieran, he shared that every child diagnosed with brain cancer being treated at Dana-Farber is now offered genetic profiling testing to identify any genetic irregularities or mutations and possible targeted therapy options to individualize their brain tumor treatment. This is known as precision medicine. A child who has brain surgery at Dana-Farber now has a sample of their tissue rushed directly to the lab and researchers start working on analyzing that tissue to identify potential targets and additional information to help direct their treatment. In addition, these tumor cells are grown in the lab so additional research can be done, including testing potential drugs to see if they have an impact on these tumor cells. Treatment for these young patients may include a clinical drug trial based on the information gained in analyzing these tumor cells. Additional treatments available at Dana-Farber for children with brain tumors include traditional radiation and chemotherapy as well as immunotherapy clinical trials. We know that Anna received the best care available at the time at Dana-Farber and more options and clinical trials than we would have received elsewhere, but we are so grateful that children treated today have so many more treatment options available to them because of this critical research now being conducted.

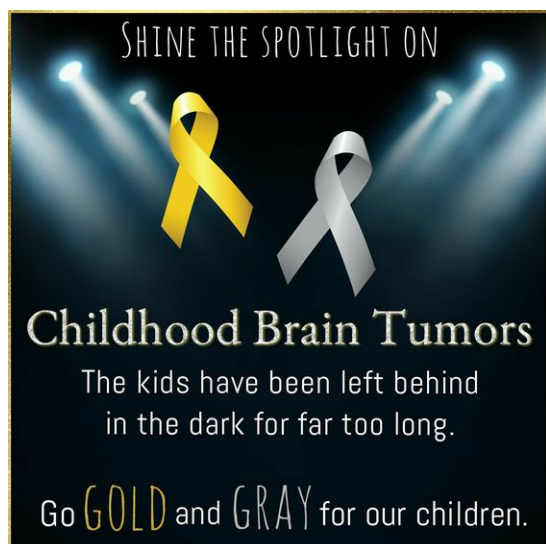




## MAY IS BRAIN TUMOR AWARENESS MONTH

### DID YOU KNOW ...

- An estimated 700,000 Americans are living with a brain tumor.
- The average survival rate for all malignant brain tumor patients is only 34.7% but there are still rare childhood brain tumors including Gliomatosis Cerebri and DIPG with a survival rate closer to 0.
- Pediatric brain tumors are the leading cause of cancer-related deaths among children and adolescents.
- Brain and CNS (Central Nervous System) tumors are the most prevalent form of pediatric cancer in kids under 19.
- It is estimated that more than 28,000 U.S. children (0-19 years of age) are living with a brain tumor.
- There are more than 130 different types of brain tumors
- More than any other cancer, brain tumors can have lasting and life-altering physical, cognitive, and psychological impacts on a patient's life.
- Despite the number of brain tumors, and their devastating prognosis, there have been only 4 FDA approved drugs – and one device – to treat brain tumors in the past 30 years. These four drugs have provided only incremental improvements to patient survival over the past 30 years.
- Gray is the color of Brain Tumor Awareness.



### LEGISLATIVE UPDATE

After participating in the National Brain Tumor Society's Head to the Hill event for the past two years, we understand much more clearly the importance of advocating for legislation to make a difference for children and adults with brain cancer. Although we are not able to participate this May, the AYJ Fund will be in Washington, D.C., in spirit and will continue our advocacy work by making calls, sending letters, emails



and more, and asking for face-to-face meetings with our congressional members.

We have seen advocacy work. One of the important pieces of legislation we advocated for over the past two years was passage of the

Childhood Cancer STAR (Survivorship, Treatment, Access and Research) Act. This legislation will improve biospecimen collection in childhood cancer, improve data collection and tracking of childhood cancer incidences, and stimulate the development of childhood cancer survivorship models. Pediatric brain tumor research and care would benefit greatly from this legislation. We are pleased to share that this legislation has passed the Senate and has now moved to the House of Representatives for action.



Last year in our meetings in D.C., we also pushed for increases in funding for the National Institutes of Health (NIH). This funding hit close to home as Kathy Warren, MD, of NIH and the host of our GC Conference at NIH last June, had a proposed project on Gliomatosis Cerebri research that was not funded this year. This won't stop her research on GC, but it prevents this critical research from moving ahead as quickly as we need it. Although we were pleased to see that there were increases in the 2018 federal budget for NIH, we still need to continue to fight for more. Without funding of this type of critical research, the statistics on brain cancer will not change.

## SHOP AMAZON SMILE

You can shop and help the AYJ Fund! The AYJ Fund is now on Amazon Smile. When shopping on Amazon, go first to [www.amazonmile.com](http://www.amazonmile.com) and select AYJ Fund as your charity option. From then on, every time you shop, a percentage of your purchases will go to the AYJ Fund. No cost to you! This works for all of your Amazon purchases including back to school supplies, student books, food shopping, and all those other essentials you find on Amazon. If you own a business, you can help even more by signing up now!



## HOW YOU CAN HELP

Check our Website at [www.AYJfund.org](http://www.AYJfund.org). We have printable pages of ideas of how you can help kids through the AYJ Fund at home, business, or at school.

**Donate** – We are always grateful for donations in any amount to continue our mission of smiles ... connections ... cures

**Volunteer** - Contact us at [Kathy@AYJfund.org](mailto:Kathy@AYJfund.org) and let us know you're available to help in any way.

**Support our programs** - Ask what our next Smiles project is, or send along your ideas on what we can do to raise funds, help research, and make more smiles.

**Stay connected** - Follow us on Facebook at AYJ Fund and online at [www.AYJfund.org](http://www.AYJfund.org)

**Spread the word** – Share information with family and friends on how critical increased funding for research is for childhood cancer and all brain cancers.

